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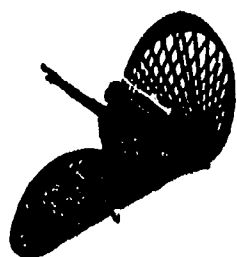
DESCRIPTORS Adolescents; \*Chronic Illness; Decision Making; Family Role; Health; Psychological Characteristics; Publications; Resources; Secondary Education; Training Methods; Vocational Education; Young Adults

## ABSTRACT

This annotated bibliography offers background information and resource information on decision-making issues for young adults with chronic conditions. The bibliography includes books, journal articles, booklets, audiotapes, and videotapes. For each item listed in the bibliography, the following information is provided: author; title; source; and abstract. The bibliography lists 16 resources on health issues, focusing on ethics, compliance, competence to consent to treatment, and the role of families and professionals; 15 items on psychosocial issues, focusing on issues both affecting and resulting from decision-making processes; 15 references on education and career issues; and 15 training materials. (JDD)

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# National Center for Youth with Disabilities

... a resource center to improve services for youth with disabilities.

## CYDLIN Reviews:

### Promoting Decision-Making Skills by Youth with Disabilities — Health, Education, and Vocational Choices (2nd Edition)

August, 1990

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Society for Adolescent Medicine  
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**The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. The Center is supported through a grant from the Bureau of Maternal and Child Health and Resources Development, Division of Services for Children with Special Health Needs, Department of Health and Human Services, #MCJ27361-010. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.**

**For additional information on the Society for Adolescent Medicine, contact:**

**Society for Adolescent Medicine  
19401 East 40 Highway  
Suite 120  
Independence, MO 64055  
816/795-TEEN**

**For additional information on the National Center for Youth with Disabilities, contact:**

**National Center for Youth  
with Disabilities  
Box 721 UMHC  
Harvard Street at East River Road  
Minneapolis, MN 55455**

**1-800-333-6293**

**or**

**612/626-2825**



National  
Center for

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# Youth with Disabilities

The National Center for Youth with Disabilities (NCYD) is pleased to send you this bibliography, *Promoting Decision-Making Skills by Youth with Disabilities – Health, Education, and Vocational Choices*. Funded by a grant from the Bureau of Maternal and Child Health and Resources Development, Department of Health and Human Services, NCYD's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation. In keeping with this mission, we are preparing a series of bibliographies targeted to specific groups. This bibliography is intended to give a wide range of professionals background information and other resources on decision-making issues for young adults with chronic conditions.

The information in this bibliography is drawn from the computerized database of the NCYD Resource Library. Contained in the Resource Library is information on journal articles, books, and unpublished documents; training materials such as videos and curricula; and information on model programs that can be used for planning purposes. A Technical Assistance Network of individuals with expertise on diverse youth- and disability-related issues is available to provide technical assistance and consulting. Additionally, the Resource Library offers access to information on federal and state case law and legislation related to youth with disabilities across many service sectors.

You can request specialized searches of the NCYD Resource Library on topics of your choosing simply by calling an NCYD information specialist. This person will then send you the requested information in a format similar to this bibliography. The minimum charge for this service is \$5.00. The database is also directly accessible, through menus or a command system, for interested individuals with their own computer and modem. The basic charge for this direct access method is \$25.00 per hour with an \$11.00 minimum use charge; the user pays any long distance charges. Either way, you can easily receive current information on youth with disabilities that is specific to your particular needs and interests.

Thank you for your interest in the National Center for Youth with Disabilities. If you would like additional information on our Center, or would like to request information about the Resource Library, please call our information specialist at 1-800-333-6293 toll-free .



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## **A. BIBLIOGRAPHIC MATERIALS**

### **I. HEALTH ISSUES**

*Decision-making issues in health care often involve significant ethical considerations as choices regarding treatment and can lead to life-threatening consequences. In the following references, ethics, compliance, competence to consent to treatment, and the role of families and professionals in health decision-making are discussed in light of the special developmental concerns for adolescents.*

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|-----------------|---|
| <b>AUTHOR</b>   | Smith PS; Goldman DS;   |
| <b>TITLE</b>    | <b>Care of the young hemophiliac. New socioeconomic demands and the changing patient-physician relationship.</b>  |
| <b>SOURCE</b>   | <i>Am J Pediatr Hematol Oncol</i> 1985 Summer; 7(2): 165-74;  |
| <b>ABSTRACT</b> | Discussion of legal and ethical issues including access to care, allocation of resources, avoidance of harm, informed consent, confidentiality and paternalism, using six case examples.  |
| <b>AUTHOR</b>   | Bush EG; Magyar PH;   |
| <b>TITLE</b>    | <b>Conflicting claims: An ethical dilemma in family-centered care.</b>  |
| <b>SOURCE</b>   | <i>J Assoc Pediatr Oncol Nurses</i> 1986; 3(3): 9-12, 27;   |
| <b>ABSTRACT</b> | Through the example of a single case study, this article describes ethical nursing approaches to interpersonal conflict in cancer care decision making. Adolescent development is taken into account. The dilemma described is disagreement on treatment continuation between an adolescent patient and her family and physician. Approaches discussed include: utilitarian or goal-based, deontological or duty-based, and rights-based or advocacy approach.        |
| <b>AUTHOR</b>   | Foley MK;   |
| <b>TITLE</b>    | <b>Children with cancer: Ethical dilemmas.</b>  |
| <b>SOURCE</b>   | <i>Semin Oncol Nurses</i> 1989 May; 5(2): 109-13;   |
| <b>ABSTRACT</b> | A discussion of ethics for health care professionals, especially pediatric oncology nurses, who are caring for children and adolescents with cancer. Many difficult decisions must be made by patients and families. The health care professional must be aware of legal and ethical decisions relating to informed consent, treatment choices, therapeutic research, when to use life-sustaining treatment, and other essential issues for youth and their families. |



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| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b> | <b>Nitschke R; Humphrey GB; Sexauer CL; et al.;</b><br><b>Therapeutic choices made by patients with end-stage cancer.</b><br><i>J Pediatr</i> 1982 Sep; 101(3): 471-6;   |
| <b>ABSTRACT</b>                                | <p>In this study, children and youth with end-stage cancer were openly informed of the recent progression of their disease, the unavailability of any other effective drugs, the improbability of a cure, and the imminence of death. Children were then given the opportunity to decide between two choices: continue chemotherapy with experimental drugs, or stop treatment and receive supportive care at home. Results indicate that those children who chose supportive care at home rarely suffered from depression or behavioral disturbances and benefited psychologically from improved communications with family and friends.</p>  |
| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b> | <b>Deatrick JA;</b><br><b>It's their decision now: Perspectives of chronically disabled adolescents concerning surgery.</b><br><i>Issues Compr Pediatr Nurs</i> 1984; 7(1): 17-31;   |
| <b>ABSTRACT</b>                                | <p>From an analysis of data gathered through structured interviews and observations of adolescents and their parents, a structural framework was derived from the critical events and management strategies that emerged. In particular, the decision to have surgery was examined: the content/meaning of the decision; strategies used to manage the decision; evaluation of the event and its management; and clinical, theoretical, and research implications of findings.</p>   |
| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b> | <b>Blum RW;</b><br><b>Compliance in the adolescent with chronic illness.</b><br><i>Semin Adol Med</i> 1987 Jun; 3(2): 157-62;  |
| <b>ABSTRACT</b>                                | <p>This article discusses issues surrounding compliance with medication, lifestyle changes, medical procedures, and appointments. Direct and indirect measures are discussed, including benefits and drawbacks. Factors found to correlate positively with compliance are: family supportiveness, positive family communications, positive family expectations of therapeutic outcome, family involvement, reasonable cost in both time and money, convenience, private providers, consistency of providers, perceived severity of illness, perceived efficacy of treatments, and level of symptom relief. Prospective measures of compliance are suggested, and a list of clinical approaches for improving compliance is provided. The author compares common perceptions of adolescent compliance with empirical findings and adolescent development.</p> |

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| AUTHOR<br>TITLE<br>SOURCE | Plotkin R;<br><b>When rights collide: Parents, children, and consent to treatment.</b><br><i>J Pediatr Psychol</i> 1981 Jun; 6(2): 121-130;  |
| ABSTRACT                  | Review of legal literature; discussion of situations where parental consent is not required, focusing on adolescents.  |
| AUTHOR<br>TITLE<br>SOURCE | Gaylin W;<br><b>The "competence" of children. No longer all or none.</b><br><i>J Am Acad Child Psychiatry</i> 1982 Mar; 21(1): 153-62;   |
| ABSTRACT                  | Attempts to define conditions that limit competence; implications for minors' right to consent, for involvement of adolescents in decisions affecting their health.  |
| AUTHOR<br>TITLE<br>SOURCE | Adelman HS; Kaser-Boyd N; Taylor L;<br><b>Children's participation in consent for psychotherapy and their subsequent response to treatment.</b><br><i>J Clin Child Psychol</i> 1984 Summer; 13(2): 170-8;  |
| ABSTRACT                  | Results of this study indicated that few youth actually participate in their own referral to psychotherapy and that this does not always reflect a lack of competence among the youth to do so. With regard to psychotherapy itself, 75% of these adolescents consented to treatment, only 60% indicated strong interest in beginning, and only 31% were deemed "motivationally ready" by the psychologists. Thus, although agreeing to treatment increased the likelihood of motivational readiness, and motivational readiness was associated with positive treatment adjustment and outcome, perceived choice is not the only important factor effecting level of commitment. |
| AUTHOR<br>TITLE<br>SOURCE | Kaplan EH;<br><b>The dilemma of disposition: Psychiatric decision-making and the college-bound high school senior.</b><br><i>Adolesc Psychiatry</i> 1982; 10: 469-83;  |
| ABSTRACT                  | The transition from high school to college can be stressful and sometimes motivates adolescents to seek psychiatric treatment. Decisions regarding the type and timing of treatment are made more difficult because of the impending separation of the student from the family. Several case studies illustrate different ways of treating college-bound adolescents with emotional disorders.   |



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| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b>               | <b>Cohen DG;</b><br><b>Treatment refusal in adolescents.</b><br><i>Semin Oncol Nurs</i> 1986 May; 2(2): 112-6;  |
| <b>ABSTRACT</b>  | Discusses non-compliance on a continuum from complete refusal of treatment to unwillingness to cooperate with a specific aspect. This issue is particularly important when teens reach the age of consent. Two case studies are used to illustrate the factors associated with non-compliance: intrapsychic issues, peer relationships, family issues, and religion. The clinical implications of treatment refusal and possible interventions are described.   |
| <b>AUTHOR</b><br><b>TITLE</b><br><b>BOOK</b>                 | <b>Ott ML;</b><br><b>When only perfect health will do.</b><br><i>Positive Approaches to Living With End Stage Renal Disease. Psychosocial and Thanatological Aspects.</i>   |
| <b>EDITOR</b><br><b>SOURCE</b>                               | <b>Hardy MA; Appel GB; Kiernan JM;</b><br><b>Praeger: New York, 1986: 152-7;</b>  |
| <b>ABSTRACT</b>  | Through this case study of a young adult, female kidney transplant patient, the author discusses the role which individual standards play in determining quality of life. For this patient, renal disease and transplant precipitated psychological problems due to her dissatisfaction with a life she perceived as imperfect. Professional and family concerns are described. Eventually, this patient effected her own death through noncompliance with treatment.   |
| <b>AUTHOR</b><br><b>TITLE</b>                                | <b>Gilgoff I; Prentice W; Baydur A;</b><br><b>Patient and family participation in the management of respiratory failure in Duchenne's muscular dystrophy.</b>   |
| <b>SOURCE</b>  | <i>Chest</i> 1989 Mar; 95(3): 519-24;   |
| <b>ABSTRACT</b><br><hr style="width: 10%; margin-left: 0;"/> | This article reports on the experiences of a clinic established specifically for patients facing impending respiratory failure resulting from Duchenne's muscular dystrophy. Previous studies had indicated that such respiratory failure was predictable and that patients and their families felt a need for more education and psychosocial support services when facing death from disease. This clinic attempted to provide more education and support and the opportunity for patients to make decisions regarding mechanical ventilation prior to actual respiratory failure. Descriptive data are discussed; case examples are included. The authors suggest that the methods used at this clinic are valuable tools for facilitating active participation of family and patient as part of the health care team. |

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| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b> | <b>Maynard FM; Muth AS;</b><br><b>The choice to end life as a ventilator dependent quadriplegic.</b><br><i>Arch Phys Med Rehab</i> 1987 Dec; 68(12): 862-4;   |
| <b>ABSTRACT</b>                                | <p>Case study of a 19-year-old male who chose to be disconnected from his ventilator 25 months after the diving accident which caused his total motor and sensory quadriplegia. Physical, medical, psychosocial, and legal circumstances are detailed. Rehabilitation staff were said to be particularly disturbed by the patient's decision due to his wealth of resources not often available to individuals who have quadriplegia and are ventilator-dependent (e.g., social support, assistive equipment, accessible home services, personal assets). The authors suggest that working toward a legal end to his life, one that would not cause his family undue hardship, may have given meaning to this patient's post-injury experience.</p> |
| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b> | <b>Bunch WH; Chapman RG;</b><br><b>Patient preferences in surgery for scoliosis.</b><br><i>J Bone Joint Surg</i> 1985 Jun; 67(5): 794-9;  |
| <b>ABSTRACT</b>                                | <p>This study surveyed teen-age patients, their parents, their surgeons, and other health professionals as to their scoliosis surgery preferences. Conjoint analysis, a technique borrowed from the fields of marketing and psychology, was employed to specifically discover respondents' preferences within the context of necessary trade-offs between options. In all groups, the risk of nerve damage emerged as the most important consideration, followed by the risk of reoperation, curve correction, and aftercare. It appears, from this study, that the values of patients, their families, and health care providers are in agreement on this issue.</p>   |
| <b>AUTHOR</b><br><b>TITLE</b><br><b>SOURCE</b> | <b>Levenson PM; Pfefferbaum BJ; Copeland DR; et al.;</b><br><b>Information preferences of cancer patients ages 11-20 years.</b><br><i>J Adol Health Care</i> 1982 Aug; 3(1): 9-13;  |
| <b>ABSTRACT</b>                                | <p>Preferred sources of information analyzed by diagnosis, race, gender, time since diagnosis, and phase of illness. Overall, physicians were the most frequently preferred source of information.</p>  |

## **II. PSYCHOSOCIAL ISSUES**

*Psychosocial issues either affecting or resulting from specific decision-making processes entail a wide range of concerns: sexuality, risk-taking, privacy, family relations, moral judgments, and self-esteem. Discussed with reference to professionals, adolescents, and their families, the following references elaborate on these concerns.*

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| <b>AUTHOR</b>   | Jaffe LR; Aledort L;   |
| <b>TITLE</b>    | <b>Adolescents with hemophilia: Psychosocial and sexual implications of infection with the Human Immunodeficiency Virus.</b>   |
| <b>SOURCE</b>   | <i>J Adol Health Care</i> 1988 May; 9(3): 261;   |
| <b>ABSTRACT</b> | An abstract of a paper presented at the 1988 Annual Meeting of the Society for Adolescent Medicine. Fifteen adolescents who had received multiple infusions of clotting factor were interviewed. Twelve patients were aware of the association between AIDS and hemophilia; 3 denied knowing this. Five knew they were HIV positive, 2 did not want to know, 1 asked to know his HIV status, and 7 did not know. Before becoming aware of AIDS, 5 were selective in telling others of their hemophilia; since AIDS, 4 more patients have kept their disease discreet. The adolescents were more worried about rejection from sexual partners than developing AIDS. Other findings are also reported. |
| <b>AUTHOR</b>   | Senft KR; Eyster ME; Haverstick J; et al.;   |
| <b>TITLE</b>    | <b>Risk-taking and the adolescent hemophiliac.</b>   |
| <b>SOURCE</b>   | <i>J Adol Health Care</i> 1981 Dec; 2(2): 87-91;   |
| <b>ABSTRACT</b> | It is a commonly held belief that adolescents with hemophilia tend to exhibit more interest in physical risk-taking behavior than do adolescents without hemophilia. In this study, a self-administered questionnaire was used to determine risk-taking attitudes, anticipated risk-taking behaviors, and the apparent likelihood of carrying out those behaviors. Results indicate that adolescents with hemophilia do not exhibit greater risk-taking attitudes, anticipate greater risk-taking behavior, or appear more likely to carry out those behaviors than adolescents without hemophilia.  |
| <b>AUTHOR</b>   | Ditunno PL; McCauley C; Marquette C;   |
| <b>TITLE</b>    | <b>Sensation-seeking behavior and the incidence of spinal cord injury.</b>   |
| <b>SOURCE</b>   | <i>Arch Phys Med Rehab</i> 1985 Mar; 66(3): 152-5;   |
| <b>ABSTRACT</b> | This study used Zuckerman's Sensation-Seeking Scale (SSS) and lay-raters to determine the degree of sensation-seeking behavior among study participants. The SSS measures four components: thrill and adventure-seeking; experience-seeking; disinhibition; and boredom susceptibility. Analysis was stratified by age group. Findings indicated no significant differences between individuals with and without spinal cord injuries. The authors contend that this is strong evidence that there is not a premorbid personality trait that distinguishes those who later sustain spinal cord injury.   |

<b>AUTHOR</b>	Linden PG; Hostler SL; Nathan M;
<b>TITLE</b>	<b>Sexuality and the physically handicapped adolescent.</b>
<b>SOURCE</b>	<i>J Adol Health Care</i> 1981 Sep; 2(1): 81;
<b>ABSTRACT</b>	An abstract of a paper presented at the Annual Meeting of the Society for Adolescent Medicine, Oct. 1981. This research illustrates the need for health care services that include continuous education about one's disability, body functions, vocational possibilities and sexuality. For this population to reach maturity, they need knowledge to gain control over their lives, become less dependent on their families, and make realistic choices.
<b>AUTHOR</b>	Guyer MJ; Harrison SI; Rieveschl JL;
<b>TITLE</b>	<b>Developmental rights to privacy and independent decision-making.</b>
<b>SOURCE</b>	<i>J Am Acad Child Psychiatry</i> 1982 May; 21(3): 298-302;
<b>ABSTRACT</b>	Review of historical aspects of parental decision making; current issues in child rights; argument for use of developmental rather than chronological criteria.
<b>AUTHOR</b>	Bannerman DJ; Sheldon JB; Sherman JA; et al.;
<b>TITLE</b>	<b>Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap.</b>
<b>SOURCE</b>	<i>J Appl Behav Anal</i> 1990 May; 23(1): 79-89;
<b>ABSTRACT</b>	The authors believe that service providers may easily deny personal liberties to a client, usually in an attempt to meet standards, be cost effective, or satisfy individuals other than clients. Arguments opposing and favoring the right to choice are presented. The authors believe that choice and habilitation need not necessarily be in conflict. It is proposed that decision-making be an integral part of habilitation training procedures.
<b>AUTHOR</b>	Tausig M;
<b>TITLE</b>	<b>Factors in family decision-making about placement for developmentally disabled individuals.</b>
<b>SOURCE</b>	<i>Am J Ment Defic</i> 1985 Jan; 89(4): 352-61;
<b>ABSTRACT</b>	This research examines 251 cases of requests for out-of-home placement made in New York in 1980-1981. The purpose of the study was to examine how three factors – individual characteristics, family characteristics, and external/internal stressors – are related to each other and the placement decision. Families requesting out-of-home placement were compared to families seeking increased services but not out-of-home placement. Results indicate that the three factors were related to placement requests. Differences existed by age of the patients: In younger individuals (under 21 years of age), the presence of behavior problems was a significant factor; for older individuals (21 and over), family stressors, burden of care, and disruption of family relations contributed to placement requests.

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| <b>AUTHOR<br/>TITLE</b> | <b>Brotherson MJ; Houghton J; Turnbull AP; et al.;</b><br><b>Transition into adulthood: Parental planning for sons and daughters with disabilities.</b>  |
| <b>SOURCE</b>           | <i>Educ Train Mental Retard</i> 1988 Sep; 23(3): 165-74;   |
| <b>ABSTRACT</b>         | Transition into adulthood for young adults with disabilities is a major concern for families, advocates and professionals. Through telephone interviews with 48 parents of young adults with mental and physical disabilities, this study examined some aspects of parent planning for adult needs and the relationship of that planning to family functioning. The greatest needs identified by parents were residential, socialization, and employment. There was a positive relationship between planning for adult needs and family functioning, and a positive relationship between using social supports in planning and family functioning. |
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| <b>AUTHOR<br/>BOOK<br/>SOURCE</b> | <b>Turnbull HR; Turnbull AP; Bronicki GJ; et al.;</b><br><b>Disability and the Family: A Guide to Decisions for Adulthood.</b><br>Paul H. Brookes: Baltimore, 1989; 432;  |
| <b>ABSTRACT</b>                   | Practical information and steps for planning for the future of adolescents with disabilities. Includes legal, social-interpersonal, vocational, and residential options. Methods for self-assessment, self-advocacy, and lists of resources to assist in planning are included. |
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| <b>AUTHOR<br/>TITLE</b> | <b>MJS;</b><br><b>"Let Me Make My Own Decisions" — An adolescent reaches for independence.</b>   |
| <b>SOURCE</b>           | <i>Except Parent</i> 1987 Mar; 17(2): 9-12;  |
| <b>ABSTRACT</b>         | This case study presents issues of independence and over-protectiveness relevant to a 16-year-old female with a disability and her family. The author presents a conflict from perspectives of various family members. Cooperative discussion is facilitated. A creative resolution evolves and the family learns new coping strategies as a result. |
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| <b>AUTHOR<br/>TITLE<br/>SOURCE</b> | <b>National Information Center for Children and Youth with Handicaps;</b><br><b>Transition summary: Self-determination.</b><br>NICHCY, P.O. Box 1492, Washington, D.C. 20013, 1-800-999-5599;   |
| <b>ABSTRACT</b>                    | Five articles on self-determination, transitioning to adulthood, the role of the family, anger in young adults with disabilities, and a role model with a disability. Guidelines for parents in helping children achieve self-determination are provided, as well as a bibliography and list of organizations dealing with transition issues. |



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| AUTHOR<br>TITLE<br>SOURCE | Derr AM;<br><b>How learning disabled adolescent boys make moral judgements.</b><br><i>J Learning Disabil</i> 1986 Mar; 19(3): 160-4;  |
| ABSTRACT                  | In this study, adolescents with learning disabilities were found to exhibit significantly less mature moral development than their nondisabled peers. The Moral Judgment Interview was used to determine study participants' moral development in terms of Kohlberg's six stage framework. Youth with learning disabilities used moral reasoning that was more egocentric than their peers. They lacked a comprehensive social perspective, had a harder time delineating options for action, and were less able to anticipate the consequences of each option and from different perspectives. Findings suggest that moral, social, and psychological development are interdependent. Theoretical foundations for the deficits among youth with learning disabilities and specific interventions to facilitate moral development are provided. |
| AUTHOR<br>TITLE<br>SOURCE | Fine E;<br><b>Are we preparing adolescents with learning disabilities to cope with social issues?</b><br><i>J Learning Disabil</i> 1987 Dec; 20(10): 633-4;   |
| ABSTRACT                  | The purpose of this study was to determine whether or not adolescents with learning disabilities were being presented with information about social issues in comparison to their nondisabled peers. Social skills deficits, poor thinking skills, and a weak information base are suggested correlates affecting decision-making ability and predispose these adolescents to social vulnerability. The results indicated that both groups of students were presented with little information about current social issues, but students with learning disabilities received less than students without learning disabilities.   |
| AUTHOR<br>TITLE<br>SOURCE | Smith SL;<br><b>Preparing the learning disabled adolescent for adulthood.</b><br><i>Child Today</i> 1988 Mar; 17(2): 4-9;   |
| ABSTRACT                  | General review of skills necessary for adulthood that affect adolescents with learning disabilities: planning and organizational skills, responsibilities, language skills, socialization skills, problem solving and critical thinking skills, self-esteem, stress, and self-advocacy.   |



AUTHOR	Schultz JB; Adams DU;
TITLE	<b>Family life education needs of mentally disabled adolescents.</b>
SOURCE	<i>Adolescence</i> 1987 Spring; 22(85): 221-30;
ABSTRACT	The Family Life Information Inventory, modified to accommodate reading and comprehension levels of adolescents with mild or minimal mental retardation, was administered to the participants of this study. Data indicated unmet needs in six areas: basic nutrition, teenage pregnancy, developmental tasks of adolescence, sex education, marriage and parenthood, and planning/decision making. Participants indicated that they wanted more help with: decisions regarding pregnancy, setting goals and making plans, responsibilities for and effects of decisions on self and others. The authors conclude that findings indicate a strong desire to become independent, responsible decision makers among these adolescents. They suggest that family life education curricula should emphasize skills and knowledge in these areas of unmet need.

### **III. EDUCATION AND CAREER ISSUES**

*Decision-making with respect to educational and vocational issues involves adolescents' ability and willingness to participate in the planning processes; decision-making is also considered to be the goal or outcome of the planning process. The following references explore these issues regarding high school, college, and vocational placement.*

AUTHOR	Adelman HS; MacDonald VM; Nelson P; et al.;
TITLE	<b>Motivational readiness and the participation of children with learning and behavior problems in psychoeducational decision-making.</b>
SOURCE	<i>J Learn Disabil</i> 1990 Mar; 23(3): 171-6;
ABSTRACT	A brief experimental intervention was used in an attempt to enhance children's (n=85, mean age=11.7 years) motivation for participation in a psychoeducational decision-making conference. Few significant differences were found between students who either received or did not receive the intervention. Discussion focuses on the need to enhance motivation for participation in instances where students already possess the necessary skills.

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| AUTHOR<br>TITLE | <b>Adelman HS; Lusk R; Alvarez V; et al.;</b><br><b>Competence of minors to understand, evaluate, and communicate about their psychoeducational problems.</b>   |
| SOURCE          | <i>Prof Psychol Res Practice</i> 1985 Jun; 16(3): 426-34;   |
| ABSTRACT        | Adolescents with learning and behavior problems have often been viewed as insufficiently competent to participate in decisions about their own psychoeducational treatment. These researchers examined the effect of explicit versus presumed consent or competence and self-estimates of competence. Math problems were the tasks the youths performed. In general, results indicated that these adolescents were able to understand instructions and tasks, make accurate self-estimates, convey explanations, and stay on task. Overestimates of competence, a finding in previous studies of youth with behavior and learning problems, were more common under conditions where explicit consent of the adolescent was not sought. The authors suggest that adolescent aversion to and poor performance in treatment decision making may be ameliorated by providing youth with more choices regarding participation. |
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| AUTHOR<br>TITLE | <b>Taylor L; Adelman HS; Kaser-Boyd N;</b><br><b>Perspectives of children regarding their participation in psychoeducational decisions.</b>  |
| SOURCE          | <i>Prof Psychol Res Practice</i> 1983 Dec; 14(6): 882-94;  |
| ABSTRACT        | In this study, students in a program designed to address learning and behavior problems were asked to state their desires regarding participation in the planning of their own education and treatment. Most students wanted to participate in such decisions, perceived themselves as capable of such participation, and did not expect negative effects from participation. Most students' behavior was consistent with these stated intentions and expectations: they did participate in decisions, judged their actions effective, and few experienced negative effects. |
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| AUTHOR<br>TITLE | <b>Taylor L; Adelman HS; Kaser-Boyd N;</b><br><b>Minors' attitudes and competence toward participation in psychoeducational decisions.</b>   |
| SOURCE          | <i>Prof Psychol Res Practice</i> 1985 Apr; 16(2): 226-35;  |
| ABSTRACT        | This replication of a 1983 study found similar results: that most youth want to be involved in psychoeducational decisions; that they perceive themselves as competent to do so; that they know what outcomes they want; and that they follow through if given the opportunity. Going beyond the first study: age was positively correlated with interest and follow-through; most participants wanted to improve their skills regarding the psychoeducational decision-making process; parents and teachers rated the effectiveness of the adolescents who participated as high. The authors suggest that these data indicate the value of offering instruction in effective participation along with participation itself. |

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| AUTHOR<br>TITLE | Stone CA; Forman EA;<br><b>Differential patterns of approach to a complex problem-solving task among learning disabled adolescents.</b>  |
| SOURCE          | <i>J Spec Ed</i> 1988 Summer; 22(2): 167-85;   |
| ABSTRACT        | This study uses Piagetian theory (isolation of variables strategy) to assess the problem-solving skills of adolescents with learning disabilities (LD). Fifty-eight 9th graders with LD, 31 normally achieving (NA) 9th graders, and 14 NA 4th graders were tested to assess data gathering skills, reasoning, and use of examiner guidance. Cluster analysis identified differential patterns of performance. The authors concluded that differential patterns of learning difficulties may require more specialized intervention strategies. |
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| AUTHOR<br>TITLE | Vaughn S; McIntosh R;<br><b>Interpersonal problem-solving: A piece of the social competence puzzle for students with learning disabilities.</b>  |
| SOURCE          | <i>J Read Write Learn Disabil Int</i> 1988; 4(4): 321-34;  |
| ABSTRACT        | Elementary and secondary school students with learning disabilities (LD) participated in intervention programs designed to increase their interpersonal problem-solving skills (IPS) and thereby their social competence. The "FAST Strategy IPS Intervention" was used with elementary students resulting in increases in peer acceptance and self-perception of social acceptance by female students with LD. Adolescents with LD improved their interpersonal skills through the use of "Teaching, Learning, and Caring," a program designed for adolescents with LD or emotional disturbances. |
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| AUTHOR<br>TITLE<br>SOURCE | Mithaug DE; Martin JE; Agran M;<br><b>Adaptability instruction: The goal of transitional programming.</b><br><i>Except Child</i> 1987 Apr; 53(6): 500-505;   |
| ABSTRACT                  | This article describes adaptability instruction for adolescents with mental retardation as an instructional model which is intended to teach students to adapt to changes in work environments. The model includes four components: a) decision making; b) independent performance; c) self-evaluation; and d) adjustment. It is suggested that further development is needed in the area of adaptability instruction in order to facilitate the employability of students with handicaps. |
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| AUTHOR<br>TITLE | Schleifer MJ;<br><b>"Junior high school is a zoo"—The youngster with emotional problems in school.</b>                  |
| SOURCE          | <i>Except Parent</i> 1981 Aug; 11(4): 45-52;  |
| ABSTRACT        | Case presentation of the family decisions involved with the choice of school for an adolescent with emotional problems. |

**AUTHOR** Agran M;Martin JE;Mithaug DE;  
**TITLE** **Achieving transition through adaptability instruction.**  
**SOURCE** *Teaching Exceptional Children* 1989 Winter; 21(2): 4-7;

**ABSTRACT** Students with learning and behavior problems often experience failure when they enter the world of work. Two major reasons are their need for a great deal of supervision and their inability to respond appropriately to the many changes that occur in work environments. This article provides teachers and work specialists with an instructional model to teach adaptability skills and presents recommendations to promote problem solving skills.

**AUTHOR** McGuire JM; Shaw SF;  
**TITLE** **A decision-making process for the college-bound student: Matching learner, institution, and support program.**  
**SOURCE** *Learn Disab Q* 1987 Spr; 10(2): 106-11;

**ABSTRACT** This article describes a systematic approach to making choices about postsecondary education for adolescents with learning disabilities. The framework takes into account the perspectives of students, parents, and high school personnel. Three components are involved: characteristics of the student, characteristics of the institution, and characteristics of the learning disability support program. The McGuire-Shaw Postsecondary Selection Guide for Learning Disabled Students (MSG) is described, and excerpts from the instrument are provided. The MSG is designed for use by guidance counselors to facilitate student decision making in this area.

**AUTHOR** Vogel SA;  
**TITLE** **Creating "safety nets" in residential settings.**  
**SOURCE** *J Postsecond Ed Disabil* 1988 Summer; 6(3): 3-6;

**ABSTRACT** Prompted by the tragic death of a postsecondary student with diabetes, a number of preventive guidelines are suggested for school and residential staff: seriously medically ill students should agree to full disclosure, a communication network should be devised, and a case manager should be designated to assure compliance with medical care.

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| AUTHOR<br>TITLE | <b>Biller EF;<br/>Career development of the learning disabled adolescent. A focus on career maturity.</b>  |
| SOURCE          | <b><i>Career Dev Excep Indiv</i> 1985 Spring; 8(1): 17-22;</b>   |
| ABSTRACT        | <b>This article discusses career maturity, or the readiness to make the educational and career decisions expected of them, among adolescents. Adolescents with learning disabilities have been found to be less career-mature than their non-disabled peers, perhaps due to the psychological effects of labelling or to the dearth of career development opportunities for students with learning disabilities who are not college bound. Suggestions are made regarding approaches to assessing and fostering the development of career maturity. Empirical data indicate that career maturity in high school is predictive of later career satisfaction and adjustment.</b> |
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| AUTHOR<br>TITLE | <b>Czerlinsky T; Jenson R; Pell KL;<br/>Construct Validity of the Vocational Decision-Making Interview (VDMI).</b>   |
| SOURCE          | <b><i>Rehab Counsel Bull</i> 1987 Sep; 31(1): 28-33;</b>   |
| ABSTRACT        | <b>Researchers investigated the validity of a Vocational Decision-Making Interview (VDMI) on rehabilitation clients with physical, mental, or emotional disabilities. Results indicate the VDMI is valid, and is a useful tool for identifying vocational decision-making problems, service needs of the individual with disabilities, and the development of new vocational education programs.</b>   |
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| AUTHOR<br>TITLE | <b>Kiernan WE; Stark JA;<br/>Employment options for adults with developmental disabilities: A conceptual model.</b>  |
| SOURCE          | <b><i>Remed Spec Ed</i> 1986 Nov; 7(6): 7-11;</b>  |
| ABSTRACT        | <b>The model "Pathways to Employment" is discussed. The model stresses individuality and availability of simultaneous choices. Supported employment is discussed in relation to individual needs.</b>  |
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| AUTHOR<br>BOOK  | <b>Wehman P; Moon MS; Everson JM; et al.;<br/>Transition from School to Work—New Challenges for Youth with Severe Disabilities.</b>  |
| SOURCE          | <b>Paul H. Brookes Publishing Co.: Baltimore, MD, 1988; 332;</b>   |
| ABSTRACT        | <b>Provides guidance to make transition planning and implementation more effective. Outlined are three basic steps leading to successful vocational placement: early planning in school years, developing and implementing a comprehensive Individual Transition Plan (ITP), and determining and choosing employment possibilities. Book provides sample forms, charts, tables, and lists which can be adapted.</b>  |



## **B. TRAINING MATERIALS**

*The training materials listed below are appropriate for use either in direct service or professional development regarding decision-making for youth with a wide range of chronic illnesses or disabilities covering diverse issues: prevention, community services, and social support.*

<b>TITLE</b>	<b>You Can Do It! A Guide to Maryland Services for Young Adults with Developmental Disabilities</b>
<b>SUPPLIER</b>	Katherine Hax
<b>ADDRESS</b>	Developmental Disabilities Council, One Market Center, Box 10, 300 West Lexington Street, Baltimore, MD 21201
<b>PHONE</b>	(301) 333-3688
<b>DATE</b>	1986
<b>ABSTRACT</b>	This free booklet addresses questions about work, residence, transportation, service delivery, and living in the community. It is printed with large type and uses easy-to-read language. It is designed to provide young people with developmental disabilities with suggested resources and solutions for day-to-day problems.
<b>TITLE</b>	<b>Don't Just Sit in a Big Green Chair! - Living with Juvenile Rheumatoid Arthritis</b>
<b>SUPPLIER</b>	LaRabida Children's Hospital, Rheumatology Program
<b>ADDRESS</b>	E. 65th Street at Lake Michigan, Chicago, IL 60649
<b>PHONE</b>	(312) 363-6700
<b>DATE</b>	1985
<b>ABSTRACT</b>	This 16 page booklet is geared towards the adolescent and how he/she can cope with juvenile rheumatoid arthritis. It includes a brief description of the disease and how to live with it. Areas such as school, sports, social activities and sexuality are addressed in a manner that can easily be understood. (Available for \$1.50 from LaRabida at Extension #520.)



<b>TITLE</b> <b>SUPPLIER</b> <b>ADDRESS</b> <b>PHONE</b> <b>DATE</b>	<b>Space Age Smarts</b> Florida Association of Pediatric Tumor Programs P.O. Box 13372, University Station, Gainesville, FL 32604 (904) 375-6848 1987
<b>ABSTRACT</b>	Space Age Smarts is an 8 1/2"x11", 12-page, full color comic book designed for hemophiliacs aged 13-16 years. An alien from the Center of Galactic Health learns about AIDS from a group of teenage earthlings. This cleverly written and imaginatively illustrated comic book encourages common sense precautions to prevent the spread of AIDS. The teens, including one with hemophilia, discuss: transmission, safer sex practices, the dangers of shooting-up, and the importance of people with hemophilia cleaning up their blood spills and disposing of needles. The fact sheet inside the back cover presents more detailed information on what AIDS is, how it is transmitted, the AIDS antibody test, symptoms, and prevention. (Purchase price is \$1.95)
<b>TITLE</b> <b>SUPPLIER</b> <b>ADDRESS</b> <b>PHONE</b> <b>DATE</b>	<b>Wasted Dreams</b> Southeastern Michigan Spinal Cord Injury System Rehabilitation Institute, 261 Mack, Detroit, MI 48201 (313) 745-9876 1988
<b>ABSTRACT</b>	Wasted Dreams discusses choices made by adolescents that may predispose them to spinal cord injuries. Specific issues are interpersonal violence and gun shootings. The notion that choices are made by individuals either to take risks or avoid risks is stressed. Consequences are discussed by youth with disabilities. (Purchase price is \$20.00 for 1/2" and \$50.00 for 3/4". Free loan in Detroit area.)
<b>TITLE</b> <b>SUPPLIER</b> <b>ADDRESS</b> <b>PHONE</b> <b>DATE</b>	<b>Hey! New Wheels</b> Southeastern Michigan Spinal Cord Injury System Rehabilitation Institute, 261 Mack, Detroit, MI 48201 (313) 745-9876 1986
<b>ABSTRACT</b>	Hey! New Wheels discusses choices made by adolescents in a variety of settings that may predispose them to spinal cord injuries. This video will rivet in students minds the devastating and irreversible consequences of a spinal cord injury. (Purchase price is \$20.00 for 1/2" and \$50.00 for 3/4". Free loan in Detroit area.)

<b>TITLE</b>	<b>Making Love-Etc. A Booklet for Young People with Physical Disabilities</b>
<b>SUPPLIER</b>	Nursing Office
<b>ADDRESS</b>	Bloorview Childrens Hospital, 25 Buchan Court, Willowdale, ON M2J4S9
<b>PHONE</b>	(416) 494-2222
<b>DATE</b>	1985
<b>ABSTRACT</b>	People with physical disabilities can and do give and receive sexual pleasure in a variety of ways. All it takes is knowledge, self-acceptance, consideration for others, imagination and patience. This booklet explores some myths and explains some problems. It then goes further and offers some solutions. (Purchase price is \$6.00 prepaid Canadian funds.)
<b>TITLE</b>	<b>Learning Experiences for Physically Disabled and Chronically Ill Adolescents</b>
<b>SUPPLIER</b>	Kluge Children's Rehabilitation Center
<b>ADDRESS</b>	2270 Ivy Road, Charlottesville, VA 22901
<b>PHONE</b>	(804) 924-5161
<b>DATE</b>	1986
<b>ABSTRACT</b>	A manual which suggests activities to use with early adolescents to improve social skills, independence, comfort in the community and assertiveness with health care professionals. Also includes exercises addressing health education issues, e.g., eating, smoking, drinking. (Purchase price: \$4.00)
<b>TITLE</b>	<b>Issues of Independence</b>
<b>SUPPLIER</b>	Young Adult Institute, PID Tapes
<b>ADDRESS</b>	460 West 34th Street, New York, NY 10001
<b>PHONE</b>	(212) 563-7474
<b>DATE</b>	1986
<b>ABSTRACT</b>	Letting go and allowing a developmentally disabled adolescent his/her independence can be a dilemma for parents. Two parents talk about their personal experiences adjusting to their sons' emerging adulthood and advise other parents to take small steps and acknowledge their adolescent's right to make mistakes. This show also highlights three developmentally disabled individuals who share their successes and struggles for independence. (30 minute videotape available on 1/2" and 3/4". Rental: \$45 plus \$4 shipping; Purchase: \$75 plus \$4 shipping)

<b>TITLE</b>	<b>Students in Transition Using Planning</b>
<b>SUPPLIER</b>	<b>PACER Center</b>
<b>ADDRESS</b>	<b>4826 Chicago Avenue, Minneapolis, MN 55417-1055</b>
<b>PHONE</b>	<b>(612) 827-2966</b>
<b>DATE</b>	<b>1988</b>
<b>ABSTRACT</b>	Total package needed to present a series of three workshops to students with handicaps at the secondary level: 1) a) A Resource Manual with outlines for each session that organize and explain the concepts to be introduced, activities in which students participate, and information handouts that explain topics such as financial aid programs, accessing employment, housing options, and post-secondary education or vocational training programs; b) A set of 45 transparencies that accompany the classroom sessions for students. Total package cost = \$280.00 (order #ST1); 2) Resource Manual sold separately = \$10.00 @ (order #ST2); 3) Set of transparencies sold separately = \$270.00/set (order #ST3). 4) Set of three information pieces for secondary students who are mentally retarded (topics: vocational rehabilitation, social work services, and self advocacy) Cost \$1.00/set (order #ST4).
<b>TITLE</b>	<b>Guardianship</b>
<b>SUPPLIER</b>	<b>Young Adult Institute, PID Tapes</b>
<b>ADDRESS</b>	<b>460 West 34th Street, New York, NY 10001</b>
<b>PHONE</b>	<b>(212) 563-7474</b>
<b>DATE</b>	<b>1986</b>
<b>ABSTRACT</b>	This show focuses on protecting the rights of an adolescent with developmental disabilities, after age 21, through guardianship. Dr. Ruth Luckasson defines guardianship and a panel of experts, including an attorney and sibling, weigh the pros and cons and debate how much power a guardian actually has. The process, procedure and legal issues to keep in mind when making this decision are also reviewed. (30 minute videotape available on 1/2" and 3/4". Rental: \$45 plus \$4 shipping; Purchase: \$75 plus \$4 shipping)
<b>TITLE</b>	<b>The Case Management Team: Building Community Connections</b>
<b>SUPPLIER</b>	<b>Metro Council Data Center</b>
<b>ADDRESS</b>	<b>Mears Park Centre, 230 East 5th Street, St. Paul, MN 55101</b>
<b>PHONE</b>	<b>(612) 291-8140</b>
<b>DATE</b>	<b>1988</b>
<b>ABSTRACT</b>	Multi-media resource to explain case management: changes in the service system, case management that addresses human values, the integration philosophy, a team approach to case management decisions, and building community capacity to support integration. (The set of materials includes a 15 minute videotape on 1/2", a 10 minute audiotape, and book. The entire set is available for purchase at \$20.00. The book alone is \$3.00.)

<b>TITLE</b> <b>SUPPLIER</b> <b>ADDRESS</b>  <b>PHONE</b> <b>DATE</b>	<b>A New Way of Thinking</b> Governor's Planning Council on Developmental Disabilities MN State Planning Agency, 300 Centennial Office Bldg., 658 Cedar Street, St. Paul, MN 55155 (612) 296-9963 1988
<b>ABSTRACT</b>	This is a national award-winning videotape about the importance of community integration for individuals with severe disabilities. The tape is divided into four segments focusing on early family support, education of individuals with developmental disabilities, transition from school to employment, and supported living arrangements. Each topic features an individual who has participated in local community-based programs and services and who is successfully integrated into the community. The tape is motivational and informative. Useful as means of promoting positive philosophy towards people with disabilities and effective service strategies. (Available on 1/2", 3/4", and Beta for free loan or \$30.00 purchase and shipping price.)

<b>TITLE</b> <b>SUPPLIER</b> <b>ADDRESS</b>  <b>PHONE</b> <b>DATE</b>	<b>Help Yourself: Tips for Teenagers with Cancer</b> Office of Cancer Communications National Cancer Institute Building 31, Room 10A24 Bethesda, MD 20892 1-800-4-CANCER 1983
<b>ABSTRACT</b>	This 40 minute free audiotape includes four radio-play stories entitled "The Day They Told You", "Your Family", "Your Treatment", and "Your Friends". This tape is designed to provide information and support for adolescents with cancer. May be used in conjunction with accompanying booklet.

<b>TITLE</b> <b>SUPPLIER</b> <b>ADDRESS</b>  <b>PHONE</b> <b>DATE</b>	<b>Approaching the Future: Cystic Fibrosis in Adulthood</b> Cystic Fibrosis Care & Teaching Center 1935 Motor Street, #316 Dallas, TX 75235 (214) 920-2361 1986
<b>ABSTRACT</b>	This 43-minute audiotape of an adult group was the project of a committee comprised of two social workers and several adult CF patients. The adult group has the desire to convey a more positive perspective on day-to-day coping with CF. During this videotape, the group discusses such issues as developing a successful adult group and why these groups are so important. Other issues include independence, employment, dating, marriage, childbirth, and dealing with the losses of group members through death. The goal of this presentation is to provide caregivers, CF adults, and CF teenagers with some helpful insights into the world that revolves around having CF. (Available for \$50.00 plus \$2.00 postage.)

<b>TITLE</b>	<b>Self-Image and Your Career</b>
<b>SUPPLIER</b>	<b>Sunburst Communications</b>
<b>ADDRESS</b>	<b>39 Washington Avenue Room SK43 Pleasantville, NY 10570-3498</b>
<b>PHONE</b>	<b>1-800-431-1932</b>
<b>DATE</b>	<b>1988</b>
<b>ABSTRACT</b>	<b>This open-captioned 38-minute videocassette shows young people why the key to good career decision-making is a clear, positive positive self-image. It helps them learn more about themselves – their personality type, aptitudes, life skills, and values – to clarify their self-image, and then use this information as a blueprint for future career choices. (Available with a Teacher's guide for \$199 plus 6% shipping and handling.)</b>

## **CYDLINE Reviews**

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**National Center for Youth with Disabilities  
University of Minnesota  
Box 721 - UMHC  
Harvard Street at East River Road  
Minneapolis, MN 55455**

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